

MA Department of Public Health Annual Family Support Plan - FY '07

Background

The Massachusetts Department of Public Health (DPH) provides programs and services that promote public health to the broad range of individuals living in the Commonwealth. DPH programs, services and educational initiatives are designed to prevent disease and disability and to reduce the impact to individuals and society of preventable health conditions and secondary effects.

The DPH Center for Community Health's (the Center) Division for Perinatal, Early Childhood and Special Health Needs (DPECSHN) offers a number of programs providing services to individuals with disabilities and their families. Following the enactment of **Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals With Disabilities and Their Families**, the Center actively examined existing programs to assess their level of meaningful family involvement. In addition, family/consumer input was sought to identify ideas about how programs and services could become more responsive and provide more flexible supports.

Overwhelmingly, individuals with disabilities and their families indicated their primary public health concern to be assistance with planning for and managing their complex medical and technological needs in the event of local, regional, statewide and/or national emergency. The Department response to this need formed the basis of our FY'04 Family Support Plan. In FY'05, DPH conducted statewide Family Focus Groups that gave families whose children have special health care needs (CSHCN) the opportunity to share their concerns, hear what DPH was planning concerning emergency preparedness and gather resources to assist in developing emergency plans for their children.

FY'06 activities that arose from the previous year's Family Focus Groups included development and publication of Frequently Asked Questions (FAQS) about emergency preparedness issues, dissemination of over 300 hundred packets of materials to support emergency planning and facilitation of community based disaster planning meetings. The Center joined with the Center for Emergency Preparedness (CEP) in developing plans to respond to pandemic flu and disseminated materials to families whose children have complex special health needs.

Overview of Family Support

The DPH retains its long history of commitment to effective, collaborative partnerships with families and works to ensure that all programming is family-centered and is responsive to family/consumer articulated needs. To ensure this strong focus on family-centered services, the Center supports a full-time position, Director of Family Initiatives. The incumbent's responsibilities include:

- Ensuring that all staff are aware of, receive information about and know how to work in partnership with families;
- Ensuring that all Center initiatives include families/consumers in planning and monitoring activities;
- Developing new and ongoing opportunities for family involvement;
- Providing training, mentoring, financial and other supports to families partnering in planning, policy making and program implementation;
- Representing the Center and its commitment to family-centered services in interagency initiatives;
- Representing the Center and its commitment to family-centered services with other organizations on the state and national level; and
- Providing the “family voice”, both personally and via inclusion of other family members and family organizations, in Center and Department activities

In addition to the broad range of public health programs and services available to families throughout the Commonwealth, the DPH is able to make small amounts of flexible funding available to families to address medical and other health-related needs not covered by other sources. Special funds help eligible families purchase (among other things) hearing aids, medications, assistive technology, respite services, home and vehicle modification and reimbursement for travel expenses. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2006, approximately 1500 families received over \$2,000,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Early Intervention Regional Consultation Program Respite Allocation, Care Coordination Family Support funding, Epilepsy Drug program and the Hearing Aid Program for Children.

Process for obtaining "substantial consultation" from families regarding flexible support needs

DPH employed a variety of mechanisms to gather information from families/consumers about their support needs. During FY'06, staff from the Department's Family Initiatives projects attended conferences, regional and local meetings and conducted focus groups and community outreach visits to share and gather information from families. All families were asked about unmet/under-met health needs, level of emergency preparedness and what assistance they would like from DPH. Every family interview included questions about how family centered were the services received from the Center and what could be done to make services more family friendly.

Additional information was obtained through the following mechanisms:

- Questions on a survey disseminated at the annual Federation for Children with Special Needs conference;
- Questions included in calls received by the Family TIES project, the statewide Information and Referral and Parent-to-Parent program;
- Questions posted to the Family TIES website;
- Questions included in calls received by the DPH Community Support Line;
- Discussions between care coordinators and their client families; and
- Information gathered by the DPH Public Benefits Specialist during her talks and trainings with individuals and families statewide.

Over 100 families responded in person and reaffirmed their interest in support about emergency planning for their children at home and school. A continued request for assistance in getting connected and having a voice in emergency planning within their communities was made. In all, over 250 families gave input regarding these questions. More than 50% indicated an on-going need for support in preparing for disasters. Most of these families had made minimal if any preparations for emergencies. Those who indicated some preparation stated that in most cases this was limited to plans for emergencies in school and that little was in place in the event of disaster while children and families were at home.

Focus Areas

I Family Empowerment

Current Activities:

Programs within the Department of Public Health seek input from practitioners, academics, consumers/families and other stakeholders via Advisory Boards. Boards generally meet at least quarterly and transmit information regarding community and individual needs directly to DPH. In addition, the following illustrate other ways the DPH promotes family participation in policy development and program planning within the Center:

- The Center applies for and receives funding from the Federal Bureau of Maternal and Child Health (MCHB) that supports many programs for women and children. Federal regulations stipulate that 30% of the funding from this Block Grant are spent meeting the needs of children with special health care needs (CSHCN) and their families. To ensure responsive, family-centered, community-based services, families of CSHCN are invited to learn about the Block Grant, participate in needs assessment activities, offer information and suggestions based upon their individual family needs and review the grant prior to submission to MCHB.
- With Federal Individuals with Disabilities Education Act (IDEA), Part C (services to children 0-3) funding, the DPECSHN supports the Early Intervention Parent Leadership Project (EIPLP). This parent-designed and parent-run project reaches out to families whose children receive Early Intervention services and offers them opportunities for leadership and lifelong advocacy skills development. Parents are encouraged and supported to partner with their own EI programs at regional early childhood events; on the state level as advisors to the DPH; as members of the federally mandated Interagency Coordinating Council (ICC) and nationally to share information about Massachusetts and to learn and bring home information from other states about opportunities for families to impact and help define services systems. In FY'06, the Massachusetts Part C program began Focused Monitoring of EI programs. This mechanism provided an additional avenue for family input regarding EI services.
- Funding from both of the above sources supports Family TIES (Together in Enhancing Support), our statewide Information and Referral network for families of CSHCN and their providers. Family TIES also serves as the Massachusetts Parent to Parent program and the Early Intervention Central Directory as well as offering training and support to interested families to take on roles within DPH programs and other public policy venues.
- Families are involved in Federal Early Childhood Comprehensive Systems Grant (MECCS), working groups.

- Families were surveyed about support needs and best uses of flexible funds through Care Coordination program and Regional Consultation Program.

New Initiatives:

- Expansion of training/match-making capacity of Family Professional Partners Institute at the Consortium for Children with Special Health Care Needs to increase numbers of families who can access skill development that will foster effective partnerships with health care organizations.
- Additional uses of Family Support funds through Care Coordination and Regional Consultation Programs based on family responses to FY'06 surveys to ensure that available funds are responsive to family identified needs.
- Increased availability of Public Benefits and Information about Services for Children with Special Health Care Needs and their Families trainings statewide.

II Family Leadership

Current Activities:

DPH supports, directly or through contracts or stipends a number of initiatives that help families to acquire leadership and advocacy skills. These include:

- Early Intervention Parent Leadership Project, a parent-designed, parent-run project that offers information, training and supports to families whose children receive Early Intervention services to assist them to partner with providers within the Early Intervention system.
- Early Intervention Hausslein Leadership Awards that offer small grants to families enrolled in EI to design and implement inclusive projects that connect their children and families to the their communities.
- Family TIES, a statewide information and referral network, offers parent-to-parent support and training to families of CSHCN and their health care providers. Families learn how to navigate the public and private service system and take on roles with health care and related organizations that impact policy development
- Mass Family Voices, a grass roots network of families of CSHCN that provides a variety of training and supports to help families learn advocacy, partnering and leadership skills. The Mass Family Voices listserv serves as forum for information exchange and policy dissemination.
- The Family Participation Working Group of the Consortium for Children with Special Health Care Needs, co-chaired by the DPH Director of Family Initiatives, assesses the status of current family-centered activities of member organizations and offers leadership training, financial support, and mentoring to family members wishing to join this policy organization.
- Support for families to attend national and statewide conferences where they can access information and skill development activities.
- On-going opportunities to indicate desired skill building training through surveys and questionnaires disseminated at conferences and workshops and at Family Initiatives projects' web sites, followed by development and dissemination of desired training.
- Participation in leadership training through MECCS pilot projects.
- A family member whose child has special health needs has become an advisor to the CICRF.

New Initiatives:

- Expanded training model that supports family members to be co-trainers, facilitators at all Early Intervention Training Center (EITC) offerings.
- "Alumni" mentoring and training activities for family members participating in Family Professional Partnership Institute activities.
- Family members who have indicated an interest in advising DPH will be invited to monthly focus groups around the state to share their insights, needs and ideas with Family TIES staff who will bring this information back to the department.
- Effort to appoint parent as a full member of the CICRF to best represent family perspective and to participate in the development of a Family Advisory Council for the Fund.

III Family Support Resources and Funding

Current and On-Going Activities:

In response to information gathered from families/consumers through out FY'04, '05, and FY '06, the Department of Public Health has continued to focus flexible family supports on assisting families whose children have special health care needs to access information and resources around preparedness in the event of emergency situations or natural disasters. DPH through its Center for Emergency Preparedness facilitates a Special Populations Working Group. Members are DPH staff as well as representatives from sister agencies. By Federal definition, individuals with special health needs are considered part of this group and their special issues around emergency preparedness are supported through the work of the group. Staff from the CEP supports the efforts of the Center's Family Initiatives programs to develop resources and information for families and the community on emergency preparedness for CSHCN and their families. The Director of Family Initiatives works with the Emergency Medical Services for Children Program to make connections between EMS and families that facilitate effective emergency response. In FY'06, all EMS providers in the state were surveyed as to their interest in enhanced communication with families whose children have special health needs. Over 1/3 of the programs indicated an interest in making personal connections with these families and assisting them in the development of their emergency plans. The Center continues to facilitate these connections as well as offer training and information about disaster planning to families and communities.

Other DPH family supports within the Center are provided by Early Intervention Regional Consultation Programs (RCPs). In FY'06, six programs statewide provided support to families of young children with complex medical needs that facilitated inclusion in community settings of family choice. In addition, RCPs disseminated over \$300,000 of respite funding for families whose children are enrolled in Early Intervention. Care Coordination and Community Support Line programs, provide additional support to families in accessing resources, navigating the health care system and obtaining information about public benefits.

DPH maintains a toll free Community Support Line available to families of CSHCN and their providers. In this, its second full year of operation, the line received 1333 calls of which 1,062 were from families. Callers receive information, technical assistance, referral and support from two dedicated Resource Specialists.

Through its Universal Newborn Hearing Screening Program (UNHS), the Department has provided support and information to over 1000 families whose children have either

not passed their initial hearing screening or have been diagnosed with hearing loss. The program employs a parent of two children with severe hearing loss as a parent consultant. This consultant makes personal contact with every family whose child receives a diagnosis of hearing loss to offer family to family support and community and statewide resources. The Program has developed a Parent Information Kit that is distributed to these families.

New Initiatives:

- The Center and CEP will continue to facilitate community-based meetings that include local emergency preparedness personnel and families whose children have complex health needs.
- Family TIES program will broaden outreach to under-served populations to ensure that information and support for emergency preparedness as well as opportunities for involvement are available.
- Family Initiatives programs will research and identify additional outside funding sources to support family emergency preparation efforts. Projects will continue collaboration with American Red Cross, foundations and area merchants to expand family supports.
- Family TIES will expand outreach to community based pediatric practices to share information about medical home concepts and family involvement in practice structures.
- Internal collaboration among Family Initiatives, Care Coordination and Community Support Unit staff will expand to ensure that a full range of services and supports are available to families.

IV *Accessing Services and Supports*

Current Activities:

The Department supports a variety of efforts to educate families/consumers about availability of and access to services. Some of these include public service announcements, Child Find, program specific newsletters such as EIPLP's **Parent Perspective** and the MassCare newsletter. CICRF and Care Coordination outreach to hospitals, schools and community settings where individuals with disabilities and their families receive services. The DPH Public Benefits Specialist provides training across the state and offers technical assistance through a toll free number. In FY'06, staff from Care Coordination, Community Support Unit and Family TIES collaborated on a series of statewide public benefits and informational meetings for families and professionals to disseminate information about available services and supports. These meetings will continue in FY'07 with the goal of reaching families who are unaware of services and supports available through DPH. Family TIES and EIPLP both maintain toll free numbers. In FY'06 over 2500 families called these lines for information, referral, Parent to Parent matches and training opportunities. These projects also host web-sites and list serves. The Center and CEP developed and made available, FAQs about emergency preparedness issues resulting from FY'05 Community Conversations with families whose children have complex health needs. UNHS distributed over 100,000 brochures in five languages to birth hospitals and birthing centers as well as over 400 Parent Information Kits. The Department provides partial support for activities of Massachusetts Family Voices including funding for the program's annual conference, "Joining Voices," and for a regional Family Voices meeting where families are given the most current information about health care policy and emerging issues and opportunities involvement.

Families are invited to attend all training provided by the Early Intervention Training Center. **Growing Up Healthy, a Child Health Diary**, was updated and now includes information on emergency preparedness. This resource, as well as "**Directions: Resources for My Child's Care**" a manual to support families of CSHCN to participate in their child's care is available to families whose children have special health needs.

New Initiatives:

- Training for care coordinators, case managers and parent professionals who support families whose children are transitioning from pediatric to adult health care system will be offered
- Joint presentations and outreach about available services will be provided by Care Coordination, Community Resource Unit and Family TIES will be given at community settings.
- Staff of FPPI will make presentations regarding opportunities for family leadership training, skill building activities and partnerships with health care organizations.

V Culturally Competent Outreach & Support

Current Initiatives:

Materials about all programs for individuals with special health needs and their families are available in a variety of languages including but not limited to; Spanish, Portuguese, Haitian Creole, Russian, Cambodian and Vietnamese. All programs have staff with multiple language capability and/or access to interpreters. The Department hires and/or contracts with individuals who are bilingual, bicultural and familiar with the culture and customs of families who utilize our programs. Outreach initiatives take place collaboratively with community-based organizations where ethnically, linguistically and culturally diverse individuals and families receive services and are comfortable. These include community health centers, WIC offices and family organizations. The Family TIES Project contracts with native Spanish and Portuguese speakers to respond to requests for information and referral, and Parent to Parent matches. Information about the availability of flexible family supports is disseminated to organizations where ethnically, culturally and linguistically diverse individuals and families gather and receive services. Project training is available in Spanish and Portuguese. The EIPLP generic newsletter is available in Spanish and disseminated to Spanish speaking families by Early Intervention Service Coordinators. TTYs are in place in all DPH regional offices. In FY'06, staff received updated training in the use of these machines. The Center has received technical assistance from the National Center on Cultural Competence (NCCC) on ways to utilize "cultural brokers" to share information about services, supports and opportunities.

New Initiatives:

- Family TIES staff will devote a quarter of their work time to identifying and building relationships with community "cultural brokers" and work towards engaging culturally and linguistically individuals in training, policy and planning activities. Contracted time with native Spanish and Portuguese speakers will be doubled to support this outreach.
- The Center will continue to work with the National Center on Cultural Competence to incorporate current research, understanding and best practices into Center initiatives.

- FPPI will do targeted outreach to Community Health Centers to identify diverse families interested in taking on partnership roles.

VI Interagency Collaboration

Current Activities:

- In FY'06, the Massachusetts Early Childhood Comprehensive Systems Project (MECCS) continued to support two interagency working groups, Family Support and Early Childhood Mental Health. A Steering Committee that guided the Project's work, composed of representatives from DPH, DSS, DMH, DEEC, CTF and the co-chairs of the working groups was formed to provide oversight and direction to the Project.
- The Department continues its active participation in the Consortium for Children with Special Health Care Needs; a group convened by New England Serve, a 20-year-old health policy and planning organization. The Consortium has a broad membership consisting of families of children with special health needs, primary care providers, academic physicians and researchers, representatives of health insurance plans and state agencies who come together to improve systems of care for CSHCN through the exchange of information, strategic thinking, and collaboration to address gaps and barriers in service systems. The DPEC SHN division director serves a member of the Consortium Steering and Executive Committees.
- Interagency Coordinating Council - A federally mandated council that advises and assists the DPH as lead agency for the MA Early Intervention System in planning, implementation and evaluation of EI services. The ICC is made up of family members of children who receive or have received EI, representatives from state agencies, early intervention programs, higher education, and other interested organizations serving young children and their families.
- DPH was awarded a federal grant for work on CAPTA, the Child Abuse, Prevention and Treatment Act. Collaborative agreements with Brandeis University, the Federation for Children with Special Needs and DSS were developed. Development of a structure for implementation will begin in FY'07.
- DPH participates in the Chapter 171 working group convened by DMR to share information about agency Family Support plans and implementation activities.

New Initiatives:

- The Department will work with the Department of Early Education and Care to incorporate and expand MECCS activities into EEC planning.
- Family Initiatives will develop and disseminate training and materials to state agencies and their vendors working with families whose children have complex health needs to assist them with emergency preparedness activities.